

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

September 14, 1998

Non Hispanic white, Higher Education

Ankeny, Iowa

Moderator: Wendy Child

SECTION 1: GENERAL IMMUNIZATIONS AND HEALTH CARE

I. Prevention

Participants mentioned the following as diseases that they are most concerned about:

- Hepatitis A
- Meningitis
- Chicken pox
- Whooping cough
- Some participants said they were more concerned about conditions such as epilepsy and asthma than contagious diseases.

Comments included:

There's a whole other way of life now because of Hepatitis A. So many things are lost because of it. For example, my son's pre-school. They have to put PlayDoh in individual bags [now]. They have to mark it and...scrub down the table...so they don't do PlayDoh on a regular basis.

It was in the newspaper that Des Moines had surpassed third world countries in terms of the outbreak for Hepatitis A.

There's another epidemic [of meningitis] starting in the public school.

We had whooping cough in our family. We had a pediatrician who didn't believe in giving the whooping cough vaccine and the oldest one got whooping cough. It was quite a struggle for her.

I'm not really worried about diseases. My oldest son got epilepsy out of the blue so I'm just worried about those type of things.

II. Immunization

A. *Reasons not to get vaccinated*

- Expense or limited access to free vaccinations
- Not caring about vaccinations
- Ignorance about how important vaccinations are
- Fear of risks associated with vaccines
- Religious objections
- Pediatrician recommends against a particular vaccine (e.g., Hepatitis B)

Comments included:

There was an article in the Des Moines Register [about] people trying to still get the money from the group the government made up to compensate families [with children] who died or were paralyzed...There are several cases that they outlined [where children] died, were paralyzed or [vaccines] changed their lives.

Maybe people can't get off work to get it done...Some of these clinics or some of these smaller doctors may not have [convenient] hours.

I was talking to [the doctor] about the Hepatitis B vaccination and the doctor thought it was foolish...He literally said it would be foolish to vaccinate...I went ahead and had [the children] vaccinated through another source...He basically said that [the recommendation to vaccinate] was a pharmaceutical company trying to push their product based on the scare.

B. Reasons to get vaccinated

- To prevent diseases
- For peace of mind
- It is parents' responsibility for their own children and to protect others from exposure
- Because the pediatrician tells you to

Comments included:

I brought this child into the world. I'm responsible for the child and that means his health, his well-being. I take that responsibility very seriously.

[It's also a responsibility to] all the people that my children come in contact with. If I don't vaccinate my children, then my children get the disease and they could pass it on to somebody else's children.

Anything you can physically do to make sure [diseases] don't happen, do it so you don't have to worry.

Your pediatrician tells you to do it. I do not really know all the research that there is to back these things up, but I trust my pediatrician.

C. Ways parents are reminded of vaccine schedule

- The doctor tells you when your child is due for a vaccine
- A record card with all the information on it
- The school keeps a record
- Flyers from pre-school about locations, times, and dates for vaccinations

We had the cards duplicated. I carry these and if my purse is ever stolen, all the records have been photocopied and put in each one of our children's files.

My card has the actual ages when they're supposed to [get vaccinated]. This is the form that's given to us from the state...When each one of my kids was born, this was included in the packet from the hospital.

I take [the cards] with me and the hospital or the pediatrician takes care of their records and I make them write it on mine.

I've gone to our pediatrician and said, 'Will you please bring these cards up to date.'

I have a hard time keeping track. Just recently, I had to go and get my oldest son's record updated so I went to the pediatrician. We switched doctors once. I don't have the card in my purse. I'm not organized. So I relied totally on the doctor to keep records and if he didn't keep them, I would not have [the information.]

D. *Methods of easier tracking*

- Several people agreed with a participant who said that a central phone number in the state to call for the information would be a good idea. However, a few participants objected to this idea. (This idea was suggested before the moderator introduced information about the registry.)

[Keeping track of the information] is just like putting pieces of a puzzle together to figure out what vaccinations they have had. It would have been nice if there was one number you could call.

In this day and age where HMOs and PPOs are taking over and your employer can switch insurance and your provider may be dropped off the list...I think it would be very difficult to get all the [information] switched. I agree that some sort of central number would be good. If physicians were held accountable for reporting every time they give immunizations to a central number and you could access that number.

I feel just the opposite. I want to be responsible for my children.

SECTION 2: IMMUNIZATION REGISTRIES

I. *Initial reactions to the idea of a registry*

- Participants had mixed reactions: Although the first person to comment was very positive about the registry, there were more participants who voiced reservations than positive reactions. Most reservations seemed to be about privacy issues and concern that computerized information could not be guaranteed to be confidential. One person was concerned about whether the registry would increase pressure on parents who object to vaccinations for religious reasons.

Comments included:

I'm all for it. If it's something that the general public can't access, I don't know why you wouldn't want it. I mean, I can keep my records, but what if my house burns down and I don't have my records?

I think it would be helpful. I would hate to miss an immunization. I don't want to do anything to make my kids sick and if this would help me remember, that would be fine...I don't understand how [the registry] could give away anything private...

It would be nice to pick up the phone, punch in a few numbers, punch in a secret code [and get] 'your daughter has had this' and write it all down...The privacy issues are the only thing I see that's negative about it.

Not without my authorization because of the privacy act. I'd have to authorize that.

My reaction is probably that I wouldn't want that...I'd have to think all this through before I can really be convinced one way or another but I'm reluctant...I can foresee some problems...I like things to be more just in my hands and not in any kind of agency hands.

I would not be for it. For one thing, you said something about it not being open to the public, but anything on a computer is open to hackers, no matter what it is...I want to know who's going to look at it and why...

I would have a couple of concerns based on whether or not this would be a state run program or whether this would be private. I would have more concerns about if it was done by a private company. I guess I would have more faith [with the state] that my child's name is not being sold. I would hope the state wouldn't be using this as a mailing list to make money off of. My other concern about privacy would be having my child's Social Security number on a computer record, but, on the other hand, his Social Security number is on a computer someplace anyway.

Are you talking about the state mandating that we [vaccinate] or are you talking about this as a service that the state will provide?

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- Most participants reacted positively to the registry keeping track of the company that made a vaccine and the lot numbers.
- There was some concern about computerizing information that is kept manually by doctors because computer hackers might gain access to it. One person pointed out that data such as a mother's maiden name is often used as a security code for bank accounts so it could be especially subject to mis-use by hackers who might obtain it from registry records.

- A few participants were also concerned about whether the registry would be guaranteed to remain limited to the content presented during the focus group.

Comments included:

If this would just simply be all this would ever amount to, maybe it's just a helpful thing. [But] pretty soon, a lot of things that maybe I would consider private...they could make that an information registry as well.

B. *Reactions to including home address and phone number*

- Most participants were uncomfortable about the inclusion of a home address and phone number. However, a few people were concerned about how else people could be located for notification about a bad lot number if necessary.

C. *Reactions to including parent or child Social Security number*

- There was very little discussion about inclusion of either a child's or parent's Social Security numbers. Some participants seemed concerned about this, but others pointed out that if neither an address or Social Security number was included, it would be difficult to notify people about a bad lot number.

D. *Reactions to including healthcare members enrollment identification (WIC, Medicaid numbers)*

[This topic was not discussed in the group.]

III. Access

A. *Who should have access*

- Parents
- Doctors or other health care providers
- Anyone authorized by a parent

B. *Who should not have access*

- Biological parents of adopted children
- Insurance companies
- Participants were unsure about whether schools should have access.
- Discussion about who should and should not have access to registry information evoked concern about how parents could verify that registry information is correct, how it can be changed if incorrect, and whose word will be accepted if the registry data conflicts with a parent's or doctor's record.

C. *Reactions to the idea of linking registry by computer to other health information systems*

[This topic was not discussed in the group.]

IV. Consent and inclusion

A. *Reactions to “opting out” option*

- Most participants were fairly comfortable with this option and believed that it provides people who feel strongly opposed to the registry a fair opportunity to opt out. However, there were some concerns that if people are notified by mail, they might accidentally discard the notice. One person also wondered if parents who opt out would have to defend their decision.

Comments included:

Fine with me.

No problem.

It gives you the choice.

If it doesn't get to you, you don't have a choice.

I'd throw it away as junk mail.

B. *Reactions to “consent” option*

- No one voiced a strong preference for this option, although one person commented:

I like [this] because I just like the idea of the permission.

- Disadvantages to this option included:

Parents not realizing they had the notice and need to respond to it.

Low response rates or low rates of providing permission resulting in small registries.

Comments included:

If you have to obtain consent, it's a conscious decision [but] the system would not be effective if there aren't many names in it.

C. Reactions to “automatic” option

- No one voiced strong concern about this option. One participant commented about this being advantageous for including information about children whose parents forget to respond or who do not care.

SECTION 3: WRAP-UP AND CLOSING

I. Most important benefit(s) of registries

- Several participants thought that the most important benefit of the registry would be the availability of immediate access to the immunization history.

Comments included:

I can't think of anything I'd have a problem with...

I live in this fear that something is going to happen to me and my husband would be lost. He wouldn't know to look in my wallet for the immunization record and sometimes I'm not sure he'd think to call the doctor. [This might help him.]

I see this as a very good program if it stays as innocent and benign as it [sounds]. I see it assisting parents and the medical profession.

II. Greatest concern(s)/biggest risk(s)

- One person was concerned that the registry would not stay as limited as described during the focus group.

III. Influence of healthcare provider in decision to participate in a registry

[This topic was added to the discussion guide after this group was conducted.]

IV. Suggestions/comments to people who are responsible for how system works

- Participants suggestions and comments included:

Just how much more information will they require of us...they'll want more information and what are they going to do with it?

I don't want the immunization registry to be a springboard to other types of medical registries. Where would it stop? I want to be the one in control of my children as a parent, not the state.

The people responsible for this registry would have to respect the rights of parents, parents' wishes and respect family privacy. This needs to be presented as an aid to parents and not as an invasion of privacy by the state.

You should try to the best of your ability to act on [all parents' views] and this means making sure that all are informed -- well-informed -- and have a choice.

Safeguard the information about children...and think carefully about how the information will be used.

The registry should be maintained for every child, but it has to be watched or administered carefully too.